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Should out of sight, mean out of mind? Challenging the role of paediatric intensive care in understanding and supporting children and families following childhood critical illness

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Several paediatric intensive care units across the world have celebrated their 50th or 60th anniversary (Argent et al., 2014). As we enter a new era of healthcare focused on prevention, self-management, integrated care and sustainability (Naylor et al., 2015), it is important to reflect and challenge the role of paediatric intensive care nursing and consider how prepared we are to address emerging and future challenges. Since the inception of Paediatric Intensive Care Units (PICUs) in the 1950's, significant medical and technological developments to support and sustain life have led to increased levels of survival of critically ill and injured children. However, the successes of paediatric intensive care have also created a new area of health issues in children and family members that is not fully understood or addressed. Some children and their families experience enduring physical, emotional, psychological and/or social adversity resulting in needs that are currently unmet (Manning et al., 2014, Manning, 2015). Therefore we aim to explicitly set out the challenges children and their families face following critical illness for PICU nurses to consider, and act on, whilst delivering care to them in the PICU.

The physiological mechanisms of paediatric critical illness together with intensive care interventions can leave children with residual physical problems. This area has been widely researched, which is not surprising due to physical aspects of healthcare having prominence and being easier to quantify. For the majority of PICU survivor's, physical functioning and health-related quality of life is adversely affected. Internationally, studies have identified that less than one-third of children are in full health at three months-post PICU discharge with most residual morbidities relating to impaired respiratory or neurological functioning, specifically sensation or motor (Ong et al., 2016).

More recently there has also been a burgeoning interest on the non-physical impact of critical illness on children and their families. The intensive care experience is recognised as being iatrogenically harmful, as it presents a variety of disease-, treatment-, and environment-related stressors (Manning, 2015). Therefore a contemporary focus on the

psycho-emotional effects has provided understanding as to the impact that this adverse event poses.

The experiences of children that are admitted to PICU appear to vary, with both positive and negative accounts identified. However, negative responses are most frequently reported with fears and anxieties associated with: perceived dangers; expectations of pain; separation from parents; and exposure to invasive procedures (Colville et al., 2008, Rennick et al., 2008). Self-esteem and perceived level of control are negatively affected up to six months post-PICU discharge. Critical illness involves a qualitatively diverse experience, which renders the child or adolescent unable to rally against the adversity to which it is exposed (Carnevale, 1997). Child survivors experience changes in relation to their behaviour, memory, attention span, self-esteem and self-confidence (Carnevale, 1997, Rennick et al., 2002). Elevated levels of avoidance, low self-esteem and depression have been reported in survivors one month post-PICU discharge. Younger children and those more severely ill are identified as having lower perceived levels of control up to six months post-PICU discharge (Muranjan et al., 2008, Rennick et al., 2002). In conjunction with the direction of the adult ICU survivor literature (Papathanassoglou, 2010), stress and in particular post-traumatic stress disorders (PTSD) have received growing attention within the field. It is evident that residual stress and associated symptoms manifest in up to one-third of PICU survivors (Bronner et al., 2008, Rennick and Rashotte, 2009).

The social challenges of surviving critical illness are less well explored within the literature. However, survivors have been found to experience increased time off school, bullying, and many outpatient and inpatient visits (Carnevale, 1997, Rees et al., 2004). The social functioning domain of Quality of Life has been reported to be negatively affected at three months post-PICU discharge (Knoester et al., 2008). Although a greater understanding is required in relation to the social domain of surviving PICU, information currently available indicates additional social adversities can manifest causing negative impact.

Similarly for the parents and siblings, having a child surviving the PICU places an enormous physical, psychological, emotional and social burden, due to evolving responsibilities and roles. As such, parents experience high levels of anxiety and PTSD symptoms post-PICU discharge attributed to unexpected admission of their child, the fear their child might die, and the occurrence of another hospital admission. A higher prevalence of stress symptoms are reported in mothers compared with fathers (Shudy et al., 2006), although this finding could be attributed to the prevalence of maternal and the paucity of paternal reports within the literature.

Collectively, the current body of literature indicates that children and families face a plethora of challenges during and following PICU. Clearly the extent to which they are affected may depend upon a number of factors including the trauma surrounding the experience, emotional resilience, and the responsiveness and support offered by intensive care staff. It is evident that the evolving science in this field has compartmentalized understanding, by focusing on specific features, attributes, disciplines or outcomes that do not appear to comprehend the whole child within the family unit. Therefore, if paediatric intensive care nurses are committed to comprehending the full impact of their care, then they need to demand, direct and develop the research in the field that reflects the whole and adopts a holistic approach. However, developing the science is only part of the way to ensuring excellence in care and outcomes for PICU survivors and their families. It is fundamental that this knowledge is brokered by health professionals to inform and advance their conduct, practices, and PICU services.

Paediatric intensive care nurses have tremendous influence and impact in addressing some of these challenges. Despite the science strongly indicating that some survivors and their families have considerable outstanding needs, there remains a distinct deficit in the services to identify needs and provide support. Although internationally there are centres that provide comprehensive follow-up programmes this is not the norm. Furthermore, in the United Kingdom disparities in service provision for adults and children

exist. For adult survivors national guidance is available that outlines care pathways and best practice benchmarks for care following critical illness (National Institute for Health and Care Excellence, 2009). However, currently no national guidance exists for the children and families that survive PICU. Therefore the development and implementation of such a guideline needs to be a priority as being without one is incongruent with drivers for quality and excellence in care, outcomes and experience.

In resource strapped times there are still things that can be done without commissioning additional services or redesigning existing ones. The notion that 'every contact counts' (NHS Future Forum, 2012) means we have to maximise every opportunity to support the often subtle and overlooked needs of these children and their families. Although we may not perceive this to be the role or focus of intensive care nursing, we are ideally placed to facilitate and offer support to enable children and families to achieve their full potential. Evident from the multifaceted nature of these challenges, a holistic ethos needs to underpin the assessment and support of the child and family. Whilst children and families remain in PICU, strategies to address and minimise factors that contribute to the harmful aspects of the intensive care experience should be implemented to reduce negative emotional responses. This could range from minimising environmental noise, eliminating unnecessary invasive interventions, ensuring children are effectively analgised, and guaranteeing parents and families are central to their child's care. Communicating with compassion and providing opportunities to commence a dialogue where concerns can be identified is also imperative. Furthermore, equipping families with appropriate information as to what they may expect, when they should seek help, and who to access is integral to enabling them to self-manage. As discussed previously in this journal, the principles of family-centred care and supporting parents in the care of their critically ill child are not yet fully explored or implemented (Latour and Haines, 2007).

It is imperative that paediatric intensive care nurses continue to review and challenge their practice and the science that informs it. In order to continue to improve the quality of

outcomes for children and their families over the next 50 years, it is fundamental that out of sight does not mean out of mind.

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